

**Delegate Al Carr
Health and Government Operations Committee
HB 1020- Developmental Disabilities Administration – Self-Directed Services (Self-Direction Act of 2022)**

Favorable Support for HB1020/SB868.

Self-direction allows an individual with intellectual/developmental disabilities, like our son Ben, have choice and control of their Medicaid waiver services, including choosing the staff that supports them and how their budget is spent so their daily activities meet their own needs and interests. We submit this testimony on behalf of Ben who is a non-verbal 17-year old with autism, intellectual disability and seizure disorder.

Ben, with our support, has recently moved from the DDA traditional service model to self-direction under the family supports waiver. We moved to self-direction because we were not able to secure supports from traditional vendors for more than 2 years. Traditional providers didn't have staff or interest in supporting Ben. We were approved for self-direction this January and Ben has been able hire 2 amazing staff who get Ben. Ben's staff provide amazing support that is driven by Ben's unique needs. Just as important, as we learned more about self-direction, we are relieved that Ben, with the support of his team now has the opportunity to make choices on how he lives his life. However, as you look under the hood of Maryland's self-direction model there are many aspects that need to be fixed. Many of which are addressed in HB1020/SB868. For instance, for several years, there has not been the ability for self-directed clients to access overnight supports – with the only option for people who need overnight supports is to be in a traditional group home model which limits choice. While Ben and other young adults with disabilities don't need overnight supports now, they will most certainly need them when their primary caregivers (their parents) have died. While DDA recently announced – just a few days ago on 3/4/22 – that the Maryland Department of Health has agreed to add overnight supports as a component of personal supports under self-direction, the announcement is not a guarantee that these supports will be available in perpetuity. The Department of Health has taken away this support and others in the past. As such, it is extremely important that these foundational supports be documented in legislation and cannot be changed by new administrative leadership in the future. Ben and other self-directed individuals should be able to continue to have guaranteed choice and control over their Medicaid waiver services as is the case in many other states. IHB1020/SB868 – the Self Directed Services Act, addresses this and many of other existing problems with how self-directed services are currently administered in Maryland.

Lastly, this legislation does not come with a price tag. It is cost neutral.

As family members of someone with a developmental disability, we ask for your uncompromising support of the right to choose the types and intensity of supports and services that are received. **Please vote to recommend passage of this bill, HB1020, out of committee.**



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Ben and his self-directed caregiving team: Choice and Control make the good Life Possible!

If the SB868/HB1020 the Self-Direction Act becomes law, it will:

- provide training and materials on self-directed services be to CCSes;
- require CCSes to annually inform waiver all participants of their right to self-direct;
- confirm the ability of participants to hire family as staff according to federal guidelines;
- restore self-directed Awake Overnight Supports for all those with a documented need;
- keep participants updated on the status of their PCP (person centered plan) throughout the creation, revision, and approval process;
- reinstate support broker role and hours;
- reimburse wheelchair-accessible and other modified vehicle owners to for mileage when the participant is a passenger, regardless of who is driving;
- remove competency requirements and provide for team support of participants;
- establish parity between self-directed and traditional services so participants in self-direction have equal access to the services they need;
- increase flexibility in Individual Family Directed Goods & Services (IFDGS)